

***The Effect of Education and Stress Reduction Programs on
Feelings of Control and Positive Lifestyle Changes in
Cancer Patients and Survivors***

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On a biological level, cancer is defined as a disease caused by an uncontrolled division of abnormal cells in a part of the body (American Cancer Society 2012). The psychological impact of living through a cancer diagnosis can be just as profound as the biological cancer growth and the physical changes it may create in an individual. Survival is just as much an emotional task as it is a physical one. Fear, uncertainty and helplessness are all emotions that can occur before, during and even after treatment and can cause a person to feel they have lost control over their daily lives and their future. This paper suggests that community programs can be effective in helping individuals affected by cancer regain their sense of control over their lives by encouraging positive lifestyle changes through a strong focus on education and stress reduction.

In the fall of 2011, I was given an opportunity to conduct a service-learning project through an introductory biology course at Northampton Community College in Bethlehem, PA. I was able to carry out this independent service-learning project at a local non-profit organization known as the Cancer Support Community (CSC) of the Greater Lehigh Valley. The CSC is part of a larger national non-profit organization that offers support groups, stress reduction programs and educational programs free of charge to anyone with a cancer diagnosis as well as their friends and family members. One program in particular that the CSC offers is Healthy Cooking, a monthly cooking class that showcases nutritious and delicious foods, and allows program participants to create the meal themselves. These classes introduce participants to healthy foods and recipes while enabling them to connect with others who share similar experiences. Because of my culinary background and personal passion towards food and nutrition, I was given the opportunity to assist with the program and draw from this experience for my service-learning project.

The foundation of nutrition is the biological and chemical components that make up the foods we eat each day to nourish and support our bodies. Numerous studies have been published documenting the relationship between lifestyle changes and cancer, though much of the data is inconclusive, with many contradictory results, and with results differing with the different forms of cancer. A review of the current state of research on nutrients and diet can be found at the American Cancer Society website (American Cancer Society 2011).

A newly diagnosed cancer patient has an overwhelming amount of information available through the internet and mass media, some of which can be contradictory or derived from unreliable sources. Despite the lack of clearly defined cancer nutrition guidelines, many people do in fact change their diets after diagnosis.

In collaboration with the healthy cooking program's instructor, Gale Maleskey R.D., and the Cancer Support Community's program director, Jennifer Sinclair M.S.W., we formulated an original service-learning project based around the healthy cooking classes. My time spent with the program allowed me to observe, communicate, and develop relationships with individuals whose lives have been impacted by cancer.

For the project we developed a survey that would enable us to observe and document the dietary changes made by individuals affected by cancer, particularly those who had attended the

CSC’s Healthy Cooking program. We could then compare and contrast these answers to those given by non-participants. We hypothesized that the Healthy Cooking program participants, in contrast to those who had not participated in this particular program, would provide answers demonstrating a stronger belief in the relationship between diet and cancer and would indicate they had made personal dietary changes.

To test the hypothesis, the survey was created and distributed to Cancer Support Community participants. It contained a series of questions related to personal diet and nutrition choices. Seventy total surveys were mailed to CSC program participants. Half of the surveys were sent to the experimental group consisting of people who had previously attended the CSC Healthy Cooking class. The other half were sent out to people in the control group, CSC members who had not previously participated in the Healthy Cooking class. Past research had been conducted at the CSC so we followed the organization’s established protocol by clearly disclosing to the survey participants the voluntary nature, use, intent and confidentiality of the research project.

Due to the fact that not only cancer patients and cancer survivors are allowed to participate in CSC programs, but their friends and family members as well, we were not able to discriminate when sending out the surveys. To remedy this, the first question on the survey was designed to distinguish whether or not the survey participant was a person with cancer/cancer survivor, spouse/partner, friend, or family member.

Twenty-seven surveys were returned from the experimental group, twenty of which were indicated as cancer patients/survivors, and the remainder indicated to be a spouse/partner, friend, or family member. To properly compare results, the twenty participants indicating they were cancer/cancer survivors, were labeled as Experimental Group #1. The entire group as a whole, including the twenty cancer patients/cancer survivors, four spouse/partners, two family members and one friend were labeled as Experimental Group #2. Because the control group contained nine cancer patients/cancer survivors and only one spouse/partner, the group as a whole was simply labeled as the Control Group.

Results from the surveys were tallied and expressed as a percentage of total participants for each group as displayed in the following data tables.

What is your main source for nutrition information? (With option to choose up to three)

Books/Literature
 Doctor/Physician
 Family/Friends
 TV/News Media
 Support Groups
 Registered Dietitian
 Holistic Nutritionist
 Internet
 HCSC-GLV Healthy Cooking Class

	Exp 1	Exp 2	Control
	80%	74%	70%
	30%	30%	60%
	30%	26%	30%
	20%	15%	20%
	5%	11%	10%
	30%	26%	20%
	5%	15%	0%
	30%	33%	20%
	50%	52%	0%

How much of a role do you believe diet plays in cancer survivorship?

(very little) 1	0%	0%	0%
2	0%	0%	10%
3	5%	11%	20%
4	35%	26%	40%
(greatly) 5	60%	59%	30%

How drastically have you changed your diet since you or your loved one's diagnosis of cancer?

(very little) 1	5%	4%	10%
2	0%	4%	10%
3	35%	30%	20%
4	40%	37%	60%
(greatly) 5	20%	22%	10%

In what ways have you altered your diet? (Indicate all that apply)

Less Animal Products	45%	44%	50%
Vitamins/Supplement	50%	48%	50%
More Dairy	5%	4%	0%
More Protein	45%	41%	20%
More Veggies	90%	85%	70%
More Fruits/Berries	75%	74%	70%
Less Dairy	35%	33%	30%
Less Red Meat	65%	63%	60%
More Whole Grains	60%	56%	70%
Juicing/Smoothies	25%	22%	20%
Fish Oil	30%	30%	40%
More Fish	40%	37%	20%
Less Carbs	35%	33%	30%
Low Fat	40%	30%	40%
Less Sugar/sweeteners	60%	59%	30%
Hormone-Free Milk	20%	15%	0%
More Organic Produce	40%	33%	20%

How often do you prepare meals at home?

(very little) 1	0%	0%	0%
2	10%	11%	20%
3	5%	4%	10%
4	15%	19%	10%
(frequently) 5	70%	63%	50%

How comfortable are you with cooking and/or trying new and different foods?

(not comfortable) 1	0%	0%	0%
2	0%	4%	10%
3	10%	11%	30%
4	15%	15%	30%
(very comfortable) 5	70%	63%	20%

There were some obvious differences between the experimental and control groups, which illustrated a greater level of changes in dietary habits. For example, 60% of participants in the experimental 1 group versus only 30% of the control group reported a 5 (greatly) when asked “How much of a role do you believe diet plays in cancer survivorship?.” The same was true for the reduction of sugar and sweeteners between the experimental and control groups, with 60% versus 30%. Sucrose, or table sugar, is a disaccharide and part of the carbohydrate family (Campbell and Reece 2008). Though there are many different types of sugar, this one seems to come under fire the most. Consumption of this tasty food additive has become a hot topic in the cancer community with claims that it possesses cancer causing and cancer promoting qualities. Although there is no definitive ruling on its ability as a substance to cause or promote cancer, the overconsumption of sugary foods has been associated with other conditions such as "sugar consumption" obesity, which may be linked to some types of cancer (Taubes 2011).

90% of the first experimental group versus 70% in the control group reported adding more vegetables to their diet. Adding additional daily servings of fresh fruits and vegetables has been widely publicized as a cancer prevention tool (Steinmetz and Potter 1996) and even a treatment in some cases, due to the diverse nutrient content found in these types of foods. On the other hand, clinicians sometimes discourage fresh fruits and vegetables in their raw form. Some patients undergoing chemotherapy experience a condition known as neutropenia due to a compromised immune system and low white blood cell count. Uncooked fruits and vegetables are then avoided because of their ability to carry bacteria (Fox and Freifeld 2012).

The study was extremely preliminary. Its main purpose was to utilize the survey and cooking classes as an observational tool rather than to produce usable statistical data. It was not the survey findings that became the ultimate focus of the study, but rather a new hypothesis that was later formulated based on questions that arose after evaluating the initial results. It appears that some people chose to initiate certain types of dietary changes despite the lack of definitive evidence from the scientific community that certain foods can change cancer outcomes post-diagnosis. Why? It could simply be because of the hope for a change in health outcomes, or because food is a conceivable controllable area of life. Perhaps lifestyle changes created an increase in positive feelings towards their health outcomes, but what causes the desire and perceived ability to move forward with a personal life change?

When assisting with the healthy cooking classes, I noticed something about the program participants. They had great enthusiasm and joy. One may not expect such a lively group in a room full of people who had or were currently battling cancer. Many participants were very talkative and eager to share the personal changes they had made to their own eating habits, whether it was new ingredients added, or certain types of foods eliminated altogether from their diets. Perhaps they did or did not believe that what was put into their bodies would have an

effect on their future prognosis, but for the moment it appeared to be an area of life that could be controlled when so many other things were uncertain.

Upon completion of the service-learning component of the project I decided to continue the study with a psychological focus rather than a biological one. The survey results in conjunction with my direct interaction with program participants during the cooking classes led me to re-evaluate focusing solely on dietary changes and the nutrition mindset. My follow-up research focus would address the root causes and effects of why people affected by cancer embrace healthy lifestyle changes and how those healthy lifestyle changes impacts their lives. This research would be based on the creation of a new psychological control hypothesis and would include healthy diet changes based on the nutrition recommendations of the American Cancer Society. It would also include the addition of other healthy changes such as initiating or increasing exercise routines, creating and maintaining positive relationships, and practicing meditation (Tacón, Caldera and Ronaghan 2004) which all may lead to the known benefit of stress reduction (Aldwin and Yancura 2010).

Lifestyle changes that contribute to stress reduction during cancer could be the difference between life and death. There is significant scientific evidence identifying a link between increased levels of the stress hormone, cortisol, and a weakened immune system. A weakened immune system can lead to a greater rate in the progression of some types of cancer (Giese-Davis et al. 2006). Therefore, theoretically, a reduction in stress obtained through a regained sense of personal control and healthy lifestyle activities could potentially impact an individual's health outcomes in relation to cancer.

I began to speculate that with further research and investigation into the subject, we could develop evidence to support a new hypothesis. The new hypothesis states that *community education programs targeted specifically towards individuals affected by cancer and focusing on education and encouraging positive lifestyle changes can be extremely effective in stress reduction and allowing participants to regain a greater sense of control.*

Locus of control is a theory developed by Julian Rotter which suggests that "behavior or personality is determined by (1) what you *expect* to happen following a specific action and (2) the reinforcement value attached to specific outcomes" (Taylor 2012). It is suggested by Rotter (1990) that possessing an internal locus of control may result in greater psychological well-being. Similarly the Health Belief Model proposed by Rosenstock (1974) addresses the causes for a change in health behavior as a result of a "perceived health threat" and a "perceived threat reduction." The Health Belief Model is not always effective, as can be seen in the example of a person who chooses to be in a destructive relationship. Although remaining in a destructive relationship is known as a threat, and it is also known that removing oneself from the destructive relationship can reduce the threat, many still choose to remain a part of the destructive relationship. Icek Ajzen's (1986) Theory of Planned Behavior combines the Health Belief Model with a plan of action for changing behavior involving three main components: attitudes towards the specific action, subjective norms regarding the action, and perceived behavioral control. A cancer diagnosis is often a significant catalyst for making personal changes that could have been afforded prior to diagnosis. The difference between people making positive changes that will lead to regained control, stress reduction, and better health outcomes and those who do not can be explained in part by the Health Belief Model and the Theory of Planned Behavior. The Cancer Support Community offers educational programs, matched with a positive supportive community atmosphere, which can reinforce "normative beliefs." This type of environment acknowledges positive lifestyle changes such as diet and exercise as "acceptable norms." It also

fosters “motivation to comply” through positive peer pressure. Lastly, it allows for “perceived behavioral control” in which the individual believes that the changes can realistically be made. These steps allow for a back and forth exchange between making changes and feeling a greater sense of control (Taylor 2012).

The Cancer Support Community offers many programs that reinforce healthy lifestyle choices such as yoga, meditation, educational seminars, healthy cooking classes, and focused support groups. When participants attend a program, they are asked to complete a workshop evaluation upon conclusion of the program session. These surveys are then compiled and entered into a database. Questions asked on these evaluations relate to decreased psychological distress, increased quality of life, new attitude toward the illness and/or treatment, increased feelings of hope, increased feelings of control, feeling less alone, and an increased connection with others who share similar concerns. As a whole, based on 1,256 workshop evaluations from a variety of programs offered by the organization, the results were overwhelmingly positive. Individually when analyzing a smaller sample size limited to ten participants after a Healthy Cooking Class, results were similar to that of the overall grouped results.

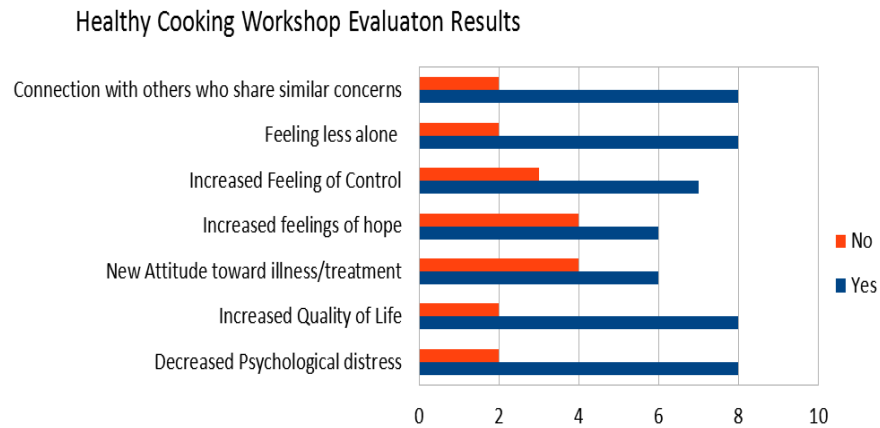


Figure 1 Healthy Cooking Workshop Evaluation Results

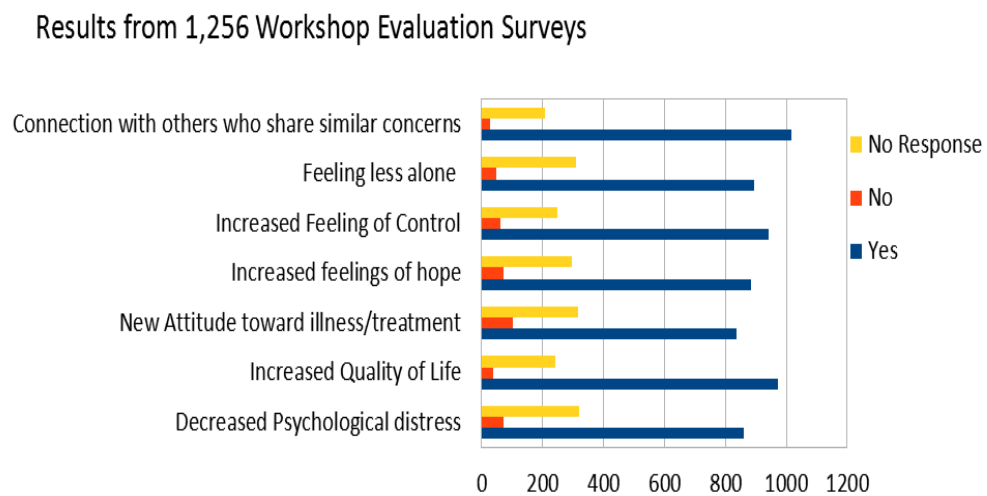


Figure 2 Results from 1,256 Workshop Evaluation Surveys

In an effort to further investigate lifestyle changes and control, a focus group was organized consisting of seven Cancer Support Community program participants. Some were current cancer patients, others were survivors, but all maintained active involvement in the organization. The goal of the focus group was to address times of helplessness, how a sense of control was lost and/or regained, and why, if any, lifestyle changes (diet, exercise, meditation, etc) were made after diagnosis. Before the focus group began participants were asked to complete an eighteen question Multidimensional Health Locus of Control Scale (MHLC). This scale rates an individual's locus of control which is defined as the "extent to which people perceive outcomes as internally controllable by their own efforts and actions or as externally controlled by chance or outside forces" (Myers 2008). This particular scale is used to rate those experiencing a medical condition. The outcomes are categorized as "internal", "chance", or "powerful others" (Wallston, Stein, and Smith 1994). In this specific form (form "C") used for the focus group, powerful others is divided into subgroups of "doctors", and "other people."

From the seven MHLC's that were completed, four were scored as "powerful others: doctors", two were scored as "chance" and only one was scored as "internal," meaning that most of the participants believed that doctors were in control of the outcomes of their condition and not themselves. The results of the focus group were surprising considering we intended to prove participants possessed an inner locus of control gained by participation in the Cancer Support Community programs. The focus group discussion itself later revealed an exceptional explanation for this.

During the focus group most of the participants in the room verbalized past feelings of helplessness, intense fear and hopelessness at the point of diagnosis. It was at this time that all sense of control was lost. Powerlessness was also felt for some during treatment in which participants were unable to maintain normal routines and activities due to sickness. Everyone in the group shared experiences of times they let go of control in order to cope. Some participants did their best to continue routines while others embraced a new life path by engaging in new activities such as traveling, doing volunteer work and reconnecting with friends.

What I noticed about this group from my own perspective was that they did demonstrate a highly selective sense of control, based on the things they found that could be realistically controlled. It was an important coping mechanism for them to let go of the things they felt were beyond their control and in the hands of healthcare providers and the healthcare system itself. One focus group participant appropriately stated, "You can only do what you can do." Letting control go in certain areas seemed to enable participants to establish control in other areas of their lives, especially emotional control.

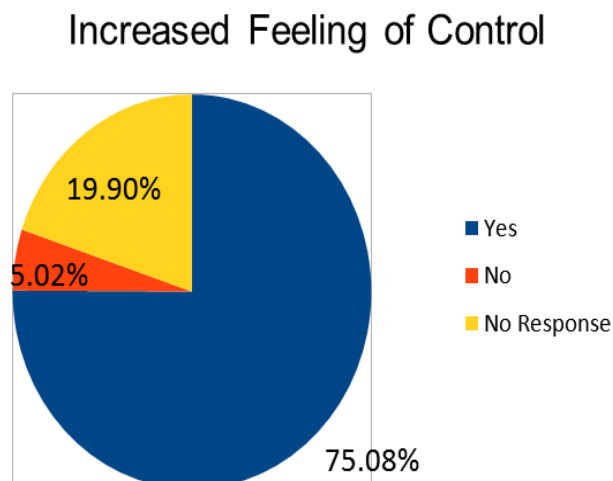


Figure 3 Increased Feeling of Control

To some degree it appeared that most if not all people in the group had altered their diets by beginning to carefully read food labels, cutting out red meat, eating more fresh fruit and vegetables, switching to organic foods and even juicing. Participants discussed engagement in various types of physical activity such as walking, jogging, general exercise and quite a few in the group were active participants in the weekly yoga program at the Cancer Support Community. Some focus group participants also described the importance of meditation, which the Cancer Support Community also offers as a program, as a way of reducing stress and putting the mind at ease. All participants expressed their profound appreciation and thankfulness for the support groups and programs offered by the Cancer Support Community. Many described it as a turning point after their diagnosis, in which they were able to regain control, become educated about their illnesses, and connect with others having similar experiences. They were also able to pass on encouragement and useful information to friends, family members and new CSC participants.

Throughout the duration of the project from the original nutrition survey, through evaluating the workshop evaluations and conducting the focus group, a large amount of meaningful data was collected. Though mostly derived from observational data, it could be speculated that a greater sense of personal control can encourage a reduction in stress and vice versa. This may then create a regained level of normalcy and the ability to reclaim pleasure from life. Based on the focus group discussion, it is also important to acknowledge the particular areas of life in which control should be exercised and when it should be released. Releasing control to outside factors can be a form of control in itself because the conscious decision is being made to allow someone or something else to take over a selective segment of life. A cancer patient cannot control how the healthcare system will process their medical claim, or how a doctor will interpret results of a recent scan, but are able to control personal mindset and outlook. This can be directly impacted by diet, exercise, education, meditation, stress reduction, and effective communication with others. The Cancer Support Community and organizations like it that offer such programs have the ability to empower patients and survivors to take control over their emotional well-being.

The initial intent of the biological service learning research project was to observe the dietary changes made by cancer patients. It later evolved into an investigation on the psychological effect that positive lifestyle changes may have on personal control and what enables these changes to occur. I believe this research is an effective preliminary model for additional community based research in service learning. Future research in a clinical setting would also be extremely valuable in evaluating the effectiveness these factors could potentially have on physical health outcomes and survivor rates of cancer patients.

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